

## **Frequently Asked Questions (FAQs) Regarding the Missouri Cancer Registry (MCR)**

### **1. What is a cancer registry? Why is it needed?**

A cancer registry is a system for collection, storage, analysis and interpretation of data on cancer patients. Cancer registries may be hospital-based or centralized.

**Hospital-based registries** use information abstracted from medical records to assess the number of diagnoses per year and frequencies by sites. The information collected consists of demographics, site of cancer, type of cancer, type of treatments, stage of disease at diagnosis and vital status. Hospital registry data are used to evaluate diagnostic and treatment practices; assess quality of patient care and hospital programs; and track outcomes. Registry data are also used to develop standards of care; develop strategic plans and measure progress; and assist hospital administrators and physicians in setting up screening programs.

**Central cancer registries** depend on the information obtained from hospital-based registries and from other sources (e.g., pathology laboratories, freestanding cancer clinics and treatment centers, physician offices, other state central registries, etc.). Data submitted by hospitals and other reporting facilities edited, then it is consolidated to remove duplicate cases. Data are then analyzed so that crude, age-adjusted and age-specific annual cancer incidence rates can be produced and trends in incidence for all cancers and for specific types/sites of cancer by age, sex and race can be assessed. These data are necessary to conduct epidemiological studies and evaluate the effectiveness or appropriateness of cancer prevention and control measures.

### **2. When was the Missouri Cancer Registry (MCR) created?**

MCR was originally created in 1972 with approximately 12 hospitals voluntarily reporting cancer cases. The original Statute 192.650 RSMO was enacted in 1984 with 1985 the first full year of implementation. The statute was revised during the 1999 session of the General Assembly when the State Legislature passed House Bill (HB) 454. After having been signed by Governor Mel Carnahan, the new legislation (192.650-192.657 RSMo 1999) became effective on 28 August 1999.

### **3. What is the goal of the Missouri Cancer Registry?**

The ultimate goal is a true population-based cancer registry. In recent years, the patterns of health care have changed, and a shift to outpatient diagnosis and treatment has been recognized. This shift has resulted in underreporting of cancer cases. Sites that are known to be underreported include melanomas of the skin (white females and males); Non-Hodgkin's lymphoma (African-American males); cancers of the oral cavity and pharynx (African-American females) and prostate cancer (all males). Without a complete data set, the Missouri Department of Health cannot conduct accurate epidemiological studies or develop a comprehensive cancer prevention and control strategy.

The Centers for Disease Control and Prevention (CDC) also recognized this trend when they established the National Program of Cancer Registries (NPCR) by enacting The Cancer Registries Amendment Act (Public Law 102-515). This legislation authorizes the CDC to provide funds to states to improve existing registries or to establish registries where they do not exist. The Missouri Cancer Registry applied for and received a grant from CDC to enhance the state registry. Stipulations of this grant require that at least 95% of new cancer cases will be reported to MCR. This goal can only be accomplished if non-hospital facilities report cancer cases to the Missouri Cancer Registry.

**4. What information is required to be submitted by reporting facilities?**

Hospitals are required to submit twenty-four (24) NPCR data elements plus 1 Missouri-required data element. The information required for non-hospital facilities is minimal and includes, but is not limited to: patient's name, address, social security number, sex, race, Hispanic origin, date of birth, date of diagnosis, site, histology, stage and treatment.

**5. Will the patient's right to confidentiality be breached if this information is reported to the Missouri Cancer Registry?**

All cancer cases submitted to MCR will be covered by the regulations within this legislation protecting the identity of the patient, hospital, physician, health care provider, pathology laboratory, ambulatory surgical center, free-standing cancer clinic or treatment center. (See also Chapters 192.067 and 192.655 of the Missouri Revised Statutes)

**6. Will physicians and other health care professionals be liable for breach of confidentiality?**

Physicians and other health care professionals cannot be liable if state law requires reporting of cancer cases.

**7. Are there any federal mandates associated with a state's central cancer registry?**

Congress established the National Program of Cancer Registries (NPCR) in 1992 by enacting The Cancer Registries Amendment Act (Public Law 102-515). Public Law 102-515 *authorizes* The Centers for Disease Control and Prevention (CDC) to provide funds to states to improve existing cancer registries; to plan and implement registries where they do not exist; to develop model legislation and regulations for states to enhance viability of registry operations; to set standards for completeness, timeliness, and quality; and to provide training.

One requirement for retention of federal funding is that "The State has a law authorizing formation of a Statewide registry and legislation or regulation in support of all 8 criteria outlined in Public Law 102-515". One criterion is completeness, defined as collection of data on at least 95% of cancer cases diagnosed or treated in the state each year.

When Missouri's existing legislation was enacted in 1984, the completeness criterion could be met with collection of hospital inpatient data. With advances in medical technology and changes in health care delivery, the completeness criterion can no longer be met solely by relying on hospital inpatient data. To maintain a population-based registry, information must also now be gathered from hospital outpatient departments, physicians' offices, freestanding treatment centers, ambulatory surgery centers and pathology laboratories.

In addition to meeting federal funding agency requirements, the state health department has the responsibility of maintaining a surveillance system that can produce accurate and complete reports on cancer incidence and trends in incidence. Therefore, the department strives not only to meet the minimum completeness requirement (95%) but also to achieve a 100% population-based central cancer registry.

**8. What is the penalty for failure to report a case?**

The penalty for failing to report is an infraction (192.657.3 RSMO). An infraction is not a crime as opposed to a felony or misdemeanor but may be punished by a fine. Chapter 556.021 RSMO defines an infraction as:

1. An offense defined by this code or by any other statute of this state constitutes an “infraction” if it is so designated or if no other sentence than a fine, or fine and forfeiture or other civil penalty is authorized upon conviction.
2. An infraction does not constitute a crime and conviction of an infraction shall not give rise to any disability or legal disadvantage based on conviction of a crime.

**9. How often will I be required to report cases?**

Reporting frequency will depend on reporting category and number of cases. Hospitals are required to submit at least quarterly with larger hospitals (greater than 500 cases annually) required to report monthly. Larger pathology laboratories may be requested to submit data on a monthly basis; small laboratories on a quarterly basis. Other non-hospital facilities will be required to report at least quarterly. **Physicians are only required to report those cases not reported by another entity, and these cases can be reported quarterly.** Physicians will be contacted on an as needed basis regarding additional data not available from other facilities (i.e., pathology labs will not have treatment information).

**10. What patients are required to be reported:** Any patient that is diagnosed and/or treated at your facility for cancer is to be reported. This may include patients that are clinically diagnosed or patients diagnosed or treated for a recurrence as well as newly diagnosed patients. Further information can be obtained by calling the number listed below.

**11. Can I request data from the Missouri Cancer Registry?**

Yes, aggregate data can be requested. No patient, reporting facility, physician or healthcare provider information will be released without permission of the same.

**Contact Information**

For further information about the Missouri Cancer Registry, contact:

Jeannette Jackson-Thompson, MSPH, Ph.D. (573) 522-2880; [jacksonthompsonj@health.missouri.edu](mailto:jacksonthompsonj@health.missouri.edu)  
Bernard R. Malone, M.P.A. (573) 522-2801; [MalonB@dhss.state.mo.us](mailto:MalonB@dhss.state.mo.us)

To make a data request, contact:

Mary Jane King (573) 522-2890; [KingM@dhss.state.mo.us](mailto:KingM@dhss.state.mo.us)

Hospital-based registrars and staff of other reporting facilities may contact the following MCR staff at 1-800-392-2829:

Sue C. Vest, CTR  
Project Manager  
[Vests@health.missouri.edu](mailto:Vests@health.missouri.edu)

Saba Yemane  
Senior Systems Analyst/Database Manager

Carlene Anderson, CTR  
Quality Assurance Coordinator

Iris Zachary, CTR  
Assistant Data Manager

Jaci Hood, CTR  
Cancer Data Coordinator

Rev 3/11/99 (scv)  
12/31/99 (scv)  
03/16/2000 (scv)  
26 April 2001 (JJT)